Orientation to Developmental Disabilities

- Colorado’s Developmental Disabilities System
- Historical themes related to the services and treatment of persons with developmental disabilities
- Basic terms

**Colorado’s developmental disabilities system (role of state, CCB, case management, PASA, advocacy)**

In Colorado 96% of individuals with developmental disabilities receive services through Community Centered Boards (CCBs). The remaining 4% receive services in state operated regional center facilities. There are twenty CCBs serving all 64 counties of Colorado. The CCB is the single entry point for community based services in each catchment area. CCBs may provide services directly or may contract with private service provider agencies, often referred to as Program Approved Service Agencies (PASAs).

Refer to Appendix B for more information on Colorado’s DD system

**DD System - DDS Rules and Regulations:**

16.224 The Colorado Department of Human Services shall purchase authorized services and supports through community centered boards or provide services and supports through regional centers or directly from service agencies under the conditions outlined in Section 27-10.5-104(4), CRS.

16.430 A community centered board shall:

1. utilize existing service agencies, social networks or natural sources of support in the designated service area.
2. encourage competition among service agencies within the designated service area to provide newly identified services and supports, the variety of service agencies available, and the demonstrated effort to purchase new or expanded services or supports other than those affiliated with the community centered board.
3. utilize state-funded services and supports administered at the local level, including but not limited to, public education, social services, public health, and rehabilitation programs.
4. ensure quality of services and supports for persons with developmental disabilities.
5. establish new services and supports for the prevention of institutionalization, the support of de-institutionalization, and the commitment to innovative, effective and inclusive services and supports for persons with developmental disabilities.
6. demonstrate effort to pursue authorized services and supports for all eligible persons within the designated service area.
16.220 Pursuant to Section 27-10.5-5(28), CRS, a service agency may be an individual or any publicly or privately operated program, organization, or business providing services or supports for persons with developmental disabilities.

**Case Management**
All individuals determined eligible for developmental disabilities services receive case management. Case management responsibilities include:
1. Intake
2. Eligibility determination
3. Development of individualized plan (IP)
4. Placement in services or on a waiting list
5. Coordination of services
6. Termination/transfer of services
7. Monitoring – quality of services, if the IP has been implemented, etc. Ensure rights of the individual receiving services are respected and protected.

**Advocacy**
1. **Definition**: Active support of the independence, rights, and choices of persons with developmental disabilities
2. **Advocates** – people advocating on behalf of persons with developmental disabilities
3. **Self advocates** – persons with developmental disabilities advocating for themselves
   There are many advocacy organizations for persons with developmental disabilities in Colorado. Some organizations, like “People First” are for self advocates. Others, like the Arc of Colorado, are comprised of individuals advocating on behalf of people with DD.

**Supplemental Materials**
- “Developmental Disabilities Services” and “Developmental Disabilities General Comparison of Community Services” – booklets developed by DDS (See Appendix B)
- “Start Here”/“Step by Step Guides” - CACCB, DDPC, DDS (to be updated in 2002)
- Handout – see subsequent pages
- CACCB website: [www.caccb.org](http://www.caccb.org)
- DDS website: [www.ochs.state.co.us/ohr/dds/DDS_center.html](http://www.ochs.state.co.us/ohr/dds/DDS_center.html)
- CACCB Recruitment Video (CACCB: 303-832-1618)
The Colorado Developmental Disabilities System

Department of Human Services

Office of Rehabilitation & Disabilities Services

Developmental Disabilities Services  Regional Centers

Community Centered Boards

Provide Services Directly  Purchase Services

How to Access Services:

- CCB INTAKE MANAGER - single point of entry
- ELIGIBILITY DETERMINATION: Eligibility Committee meets to determine if a person qualifies per the Colorado definition of developmental disability.
- IF ELIGIBLE:
  - Services begin, if available, OR
  - Wait list
- ≥ 14 years of age to be on the list for adult services
- First come, first serve
- Emergency considerations

Case Management

- The determination of eligibility for services and supports
- Service and support coordination
- The monitoring of all services and supports delivered pursuant to the Individualized Plan (IP), and the evaluation of results identified in the Individualized Plan

Resource Coordination

- Develops Individualized Plan (IP) annually
- Coordinates all services in the IP
- Assists the person to find services
- Works with the Interdisciplinary Team (IDT)
Services Available to Adults

Comprehensive Services
Supports day to day needs
Supervision
Training and habitation
Coordinate & obtain therapies; OT/PT, mental health
24 hour program

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Supported Living Services (SLS)

- For people living in their own home or with their families
- Supported Living Consultant (SC) coordinates the SLS services
- **Examples:**
  - Personal Assistance
  - Habilitation
  - Environmental Engineering
  - Professional Care
  - Dental
- Not a 24 hour/day program

Services Available to Children & Families

- Early Intervention (0-3 years)
- CES Waiver (for children with very intense needs)
- Family Support (for any families with a child who has a developmental disability)
  - Funding for costs not covered elsewhere (ex – family counseling, parent education, home modifications, respite care, etc.)
Colorado:
64 Counties
20 Community Centered Boards
See CACCB website for more information: www.caccb.org
Historical themes related to the services and treatment of persons with developmental disabilities

Prior to the 1960’s persons with developmental disabilities and their families had little or no choice for services beyond keeping their children and family members at home or sending them to state institutional facilities. Over the years Colorado has worked to promote the evolution of services delivered in the communities where the individuals with developmental disabilities live. In 1963, the Colorado state legislature authorized the state to contract with Community Centered Boards, who would serve as the entry point for locally managed community based services. The goal is to provide people with developmental disabilities the same opportunities, rights, and responsibilities as any other citizen, and to further efforts to include these individuals in all aspects of community life. Currently all but 4% of Colorado citizens with developmental disabilities receive services in their communities.

The timeline that is included in these materials provides an interesting picture of how services, terminology, and public attitude towards persons with developmental disabilities has evolved over time.

**Supplemental Materials re: History of DD:**
- Timeline - STARNET *(see subsequent pages)*
- “History of People with Developmental Disabilities” - STARNET
- “DD System and Agency Orientation: Historical Perspective” – Developmental Pathways 303-360-6600
- Laradon Library 303-296-2400
- Suggested Videos (can be ordered through [www.disabilitytraining.com](http://www.disabilitytraining.com)):
  - “Unfinished Business”
  - “Without Pity: A Film About Abilities”
  - “A Little History Worth Knowing”
  - Abandoned to Their Fate: A History of Social Policy Towards People with Developmental Disabilities“

Basic terms relative to developmental disabilities

Working in the field of developmental disabilities requires staff to be familiar with a number of terms that are specific to this field.

**Supplemental Materials re: Basic Terms:**
- Glossary of terms, DDS “General Comparison of Community Services” *(Appendix B)*
- Definitions found in DDS Regs *(See Appendix C)*
- Glossary of Frequently Used Terms – Developmental Disabilities Resource Center, (303) 233-3363
- Step by Step Guides to *be updated 2002* (glossary of common terms, etc.)
- “Common terminology” *(see subsequent pages)*
SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES: COLORADO HISTORY

Late 1800's and early 1900's

1883 The Colorado Insane Asylum (later named the Colorado State Hospital) admits its first patients to a temporary hospital until the permanent building is opened in Pueblo. P.R. Thoms is first superintendent.

1890 Population in institutions for the “feeble minded” equals 5, 254

1892 Need for institution is seen

1904-05 Bills are introduced to appropriate money for an institution but fail

1909 Bill passed to establish Wheat Ridge institution

1909 Committee on Eugenics votes to establish a subcommittee on the heredity of the feeble minded.

1910's

1910 Legislature passed legislation to provide funding for state institutions

1912 July 1—Colorado State Home for Mental Deficiencies opened with 46 “inmates”—25 men, 21 women—in Wheat Ridge. 80 technicians are employed. Classifications include: idiot, idio- imbecile, moral imbecile, low-grade imbecile, middle grade imbecile, and high-grade imbecile. The Home’s reason for opening—to offer a home to these “unfortunates” and to train them

1912 A law passed preventing marriage for “feebleminded” and allowed segregation in an institution for life or at least during reproductive period. A sexualization of all cases of reproduction occurred.

1913 Statement issued: “Owing to hereditary of defectiveness, it is very important to permanently commit the feeble minded to institutions, preventing the increase of this class of person”

1914 Committee on Provision for the feeble minded is founded. Purpose is to disseminate knowledge concerning the extension and menace of feeblemindedness and initiate methods for its control and ultimate eradication from the American People

1916 Waiting list of 100; 90 applicants

1916 3 deaths reported at Colorado State Home for Mental Deficiencies—all due to epilepsy

1916 Outbreak of scarlet fever and chicken pox

1917 Increased demand for placements—300 applicants—more money is needed for state institution

1920's
1920  Institution in Grand Junction opened in old Indian School
1920  Institutions having difficulty getting and retaining help. Forced to put up with inexperienced/incompetent help.
1925  No admission to individuals under 6 years of age. Believed a mother’s care is better for such tender ages.
1925  Institution staff’s annual salary is $194.50 ($16.21/month or $.56/daily).

1930’s
1931  121 boys/men and 112 girls/women at Wheat Ridge
1933  Association for the Study of Feeble Minded becomes the American Association of Mental Deficiency
1933-34  Statement issued: “Mental Defective child does not have the same sense of morality or decency as a normal child and cannot be taught these”
1935  People said that Mentally Defective children are a “menace to society and normal people should be protected from them.”
1936  Two institutions in Colorado to care for the “unfortunates”. Combined population of 480 with 3,000 possible cases. Unable to get funding for additional buildings. Many cases are being sent to the mental hospital in Pueblo. State is asking for appropriations of funds for nursing homes
1937  The fundamental objective of the institution is the education of the mentally defective child. Institution employees are “underpaid” and receive $35-40 per month with an average of 9.5 hours/day, 7 days a week.

Late 30’s  St. Anne’s Convalescent Home, a haven operated by Episcopalians for Psychiatric Children opens

1940’s
Early 40’s  St. Coletta’s, run by the Sisters of St. Francis, was the only residential facility of its kind between Chicago and the West Coast—located in Longmont.
1940  2,500 cases in the state in need of institutional care, 400 cases at Grand Junction, 300 at Wheat Ridge, 250 at the State Hospital at Pueblo. Generally new admissions are over 16 years of age.
1940  During the past few months, 91 changes of personnel with less than 60 on payroll (at Wheatridge)
1941  Administrative code bill was abolished for the BO commissioners which means: had to establish a permanent board of control over the institutions

1947  President’s committee for Employment of Handicapped in Washington starts
1949  Laradon Hall opens for 3 school age children
1949-50  Wallace House moves to Broomfield. (Originally called Wallace House for Retarded Children)
**1950's**

1951 National Association of Retarded Children was organized.
1952 State Home Training School—"If proper education is provided, these children can be productive members of society"
1951 First class to graduate at Wheat Ridge (students with developmental disabilities)
1952 Colorado had 1,350 exceptional children or MR people in their institutions, with a waiting list of up to 5 years
1953 100 computers in the world
1955 “First and Last class to graduate” at Wheat Ridge (students consisted of people who were misdiagnosed—all had average or above average IQ’s with highest IQ 110. Average graduating age is 34
1956 Wheat Ridge Council for Retarded Children was organized
1956 1,112 total people at 2 institutions (Grand Junction and Wheat Ridge)
1959 Wheat Ridge gets volunteers to start recreation activities for “low grade” children
1960 AAMD’s definition of Mental Retardation includes Borderline, Mild, Moderate, Severe and Profound
1950's Parents were legally bound to pay $35 per month for care of child and to furnish clothing. The county was responsible for any amount unpaid.

**1960's**

1961 Jefferson County ARC is founded
1961 Jefferson County opened its first public school class for MR children
1960 A study notes that 30 out of every 1,000 children are Mentally Retarded.
1960 A bill passed allocating state funds to build a school for the “trainable child” (IQ is less than 50)
1960 First Value Village (ARC thrift store) opens in Denver
1962 The Colorado division of mental retardation started, Dr. Wesley White is director
1962 Hope Center for the Retarded is founded
1963 CCB system formed
1962-63 Total expenditures per resident per year (at Wheat Ridge)—$2,863 or $8.40/day
Mid 60’s A grant was started to take 90 “pseudo-retardates” to Ft. Logan; it was designed to place all of these individuals in the community within 2 years. It wasn’t completed in 2 years, but by the end of the 3rd year, all 90 people were living successfully in the community.
1966-67 Total expenditures per resident per year (at Wheat Ridge)—$4,259 or $11.60/day
1968  The Special Olympics is founded by Eunice Kennedy Shriver

1968  A new law grants money to the state for Vocational Rehabilitation services (4 grants)
1. Rehabilitation services for mentally retarded
2. Project with industry for training the handicapped
3. Training
4. Develop new career opportunities

1968  74% of “inmates” have no contact with anyone outside of the institution according to a survey

1969  June—Dorothy Dean founded the agency “Closer Look” which provides information to help parents in educating their handicapped children for the real world of work

1969  Goal of Wheat Ridge—help every resident develop and move back into a less restrictive community setting

1970’s

1970’s First Winter Special Olympics held in Colorado

1972  Wheat Ridge Regional Center establishes Professional certification for staff

Ridge had 94 individuals who use wheelchairs who were unable to leave because they had only one van holding 2-3 wheelchairs. Other types of transportation were a federal mail truck without windows, which holds 5 wheelchairs at a time, but no locks for the chairs.

1973  Section 504 of the Rehabilitation Act of 1973 (the Civil Rights Act of Americans with Developmental Disabilities)—noted that individuals can assert their rights to be in a program—this helped with jobs as well as medical/dental services.

1973  Approximately 75% of the 760 residents are profoundly/severely retarded who require total care and are non-verbal, non-ambulatory.

1975  July—Legislation to provide financial assistance to states for improved education services for handicapped services (becomes IDEA in 1977)

1974  AAMR Definition of MR from subaverage to significantly subaverage.

1975  November is named “Mental Retardation Prevention Month”

1976  The Legal Center started

1976  “Model Workers” introduced

1976  Project Find survey in Jefferson county results in 2% of population diagnosed with mental retardation compared to 1.1% of the United States

1976  Three state institutions were appropriated money to build group homes

1978  Class Action Lawsuit filed in the US District Court—supposed to correct inadequate training and care for retarded citizens. A spokesperson said, “geared to correct a situation characterized as ‘totally repulsive’” The first major suit in the nation in which a state and protection and advocacy system has appeared as a plaintiff. This lawsuit was designed to speed up the deinstitutionalization process. Lawsuit filed by Colorado Association of Retarded Citizens and the Center for the Legal Advocacy also known as the Legal Center for Handicapped Citizens.

1978  A news article makes reference to an individual with “developmental disabilities”
1978  The Handicapped Student Services started at University of Southern Colorado in Pueblo

1979  March becomes “Mental Retardation Month”

1979  March 1—HB 1492 creates retardation technician specialist at institutions

1980  People First started in Pueblo

1980  National Association for Retarded Citizens changed their name to ARC

1981  Lawsuit by the ARC and the Legal Center ruled that children who are residents of Wheat Ridge were denied free and appropriate education—all handicapped children are to receive a free, appropriate public education, whether they live at home with their parents or at a state institution.

1982  Alternative Houses founded

1985  HB 1205 passed which retained the CCB system to provide services and case management as well as the first right of refusal and an appeal process if people believed their rights were violated

1987  November—The American Association for Mental Deficiency changes their name to the American Association for Mental Retardation

1980's Group Homes, PCAs, are established. Supported Living Services, Family Support Programs begin.

1990  ADA passed

1991  AAMR changes MR definition: “Mental Retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self care, home living, social skills, community use, self direction, health and safety, functional academics, leisure and work. Mental Retardation manifests before age 18.

Mid 90's  ARC (formerly NARC) changed name to the Arc of the United States

1996-97  Colorado Meeting Place started—a computer network for disability issues—for people, not agencies

1998  Study shows that more than 400,000 Coloradans have one or more physical or mental disability

2000-02  Current lawsuit demanding the state to provide services to people on waiting list.

2000's
Common Terminology

**Developmental Disability:** means a disability that is manifested before the person reaches twenty-two (22) years of age, which constitutes a substantial disability to the affected individual, is attributable to mental retardation or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions when such conditions result in impairment of general intellectual functioning or adaptive behavior similar to that of a person with mental retardation.

**Autism:** Severe communication disorders with impaired ability to communicate, understand, learn, and participate in social relationships

**Childhood/Adolescent Schizophrenia/Psychosis:** A group of severe mental disorders characterized by loss of contact with reality and disorientation. A treatable emotional illness; sometimes a childhood diagnosis of autism or pervasive developmental disorder

**Cerebral Palsy:** Permanently disabling motor disorders resulting in complete or partial paralysis of the muscles. It is caused by damage to the developing brain before, during, or after birth.

**Down Syndrome:** Formerly called mongolism. A form of mental retardation caused by improper chromosomal division at conception. Characterized by flattened facial features and causing mild to severe mental retardation.

**Epilepsy:** Abnormal brain activity causing seizures of varying types and intensity. Regulation by medication is possible in more than 60 percent of all cases. Causes include brain damage by injury or illness and chemical imbalance.

**Fragile X Syndrome:** Genetic disorder resulting from a "fragile" site on the X chromosome, severely affects males. Estimated to occur in 1 out of every 1000 male births. Females are carriers and may also exhibit learning problems.

**Hereditary Progressive Muscular Dystrophy:** A hereditary, progressive degeneration of the muscles with accompanying weakness and deformity.

**Huntington's Disease:** A hereditary disease of adults marked by irregular movements, speech disturbance, and mental deterioration.

**Klinefelters & Turner's Syndromes:** Sex-linked chromosome defects. Klinefelters affects males; Turner's affects females.

**Mental Illness:** A group of acquired, treatable emotional disturbances. Mental illness is often confused with mental retardation.

**Mental Retardation (MR):** means substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.

**PKU:** Genetic defect in which the individual is unable to break down amino acid, phenylalanine.

**Tay-Sachs Disease:** Metabolic disorder that results in paralysis, blindness, and death by age 5.
**Tuberous Sclerosis:** An inherited disorder resulting in lesions and tumors of the skin, eyes, bones, heart, nervous system, kidneys. Thirty eight percent have normal intelligence; a few lose intellectual ability as they age.

**Age appropriate skill:** a skill which someone of the same chronological age would normally perform

**Functional skill:** a skill that someone else would have to do or be paid to do if the individual does not perform it.

**Teaching in natural environments:** teaching which occurs in the real environment in which a skill will be used, i.e. street crossing on the street, bus training on buses, dressing and undressing in the individual’s bedroom

**Teaching at natural times:** teaching which occurs at the normal times when a skill is performed, i.e. bathing at night before bed or in the morning before getting dressed.

**Community-based training:** individualized teaching of specific skills within a community setting, i.e. grocery shopping at King Sooper’s, ordering at McDonald’s, stocking shelves at 7-11

**Positive behavior programs:** structured programs to teach and positively reinforce desired behavior

**Normalization:** providing experiences, opportunities, living, and working environments which are at least as good as those available to all other (“normal”) members of society